

Conflict of Roles: Enrolling one's own children in your research

Author: Eli Abernethy, BA, Ethics Fellow

Category: Participant Recruitment

Ethical Dilemma

A researcher wants to enroll his child in the study for which he is the co-investigator. The research enrolls healthy children as controls and involves placing the child in different positions and monitoring blood flow. Faced with a lack of volunteers and in a time crunch to fill a final spot in the study before funding for the research ends, the co-investigator enrolls his own child. The research group was in an ethical bind and troubled by the idea of a co-investigator using his own child as a control. They were concerned that the child would be coerced since she knew that the study was her father's job.

Expert Opinion

Researchers have long turned to their own children for recruitment into their research. In 1954, Jonas Salk injected his children with his newly developed polio vaccine, and the famed psychologist Jean Piaget studied his own children in depth for his work on child development.¹ Extreme cases of scientists conducting research on their own children extend into modern day as well. In 2009, a front page article in the New York Times detailed the case of a neuroscientist strapping a camera to the forehead of his newborn child, an MIT researcher who recorded 70% of his child's waking hours for years, and a Vanderbilt medical professor who included all 7 of his children in his research on learning problems and speech development.² On one hand, the case detailed above is benign in comparison to some of these more extreme examples; the control regimen proposes no harm to the participating child since it was a minimal risk study. On the other, the co-investigator enrolling his own child into the research study still raises several concerns, namely that of professional objectivity, patient autonomy, and informed consent.³ Should children enrolled in their own parent's research be considered an especially vulnerable population?

A review of the literature reveals a lack of official guidance on the topic. Neither federal research regulations nor The Office for Human Research Protections (OHRP) address the enrollment of children in their parent's research.⁴ As a result, decisions about the permissibility of such cases must be made by an Institutional Review Board (IRB) or ethicist. Shepherd et al. suggest two set of questions such entities may encourage, namely a set that a researcher asks themselves when considering using their own children for their research and a set that consent monitors can discuss with children when obtaining assent and parental permission:^{5,6}

Questions for Researcher:

- 1.) Why do I want my child to participate in my study?
- 2.) How will participation affect my relationship with my child in the present or future?
- 3.) Is this a joint decision that both parents support?
- 4.) Might my child feel pressure from me to participate?
- 5.) How will I avoid my child's feeling that s/he has let me down if s/he decides not to participate or to withdraw before the study is over?
- 6.) What procedural safeguards will I implement to ensure that the data related to my child are handled and analyzed in the same way as data collected from other participants?

Questions for Consent Monitor and Child:

- 1.) Why do you want to be in this study?
- 2.) Do you feel that you can say “no” if you do not want to be in this study?
- 3.) Do you feel like you could choose to stop being in the study whenever you want to?
- 4.) Your mom or dad might hear or see information gathered from you in this study. Is that okay with you?
- 5.) Would you feel comfortable with me checking in with you again? (for studies with more than one visit)

Beyond the exploration of the intentions of the parent, additional considerations about the nature of the study must also be taken into account if an investigator is to utilize his or her child for research purposes. For minimal risk studies, a child of the researcher can be enrolled if the child assents and a different parent or guardian provides parental permission, though it must be acknowledged that this may still present a risk to the parent-child relationship.⁷ It is best if another researcher (who is not the child’s parent) obtains the assent and parental permission. If the data are objective measurements, with no subjective component, the researcher who is also the child’s parent can record and analyze the data. This assumes that the data are not private, personal, or sensitive in such a way that it would be problematic for the parent to know it. If the data are subjective, another researcher should record and analyze the data, or the data should be de-identified so the parent does not know which are the child’s.

For a study that is more than minimal risk, the default presumption is that the child should not be enrolled in the study. With higher stakes and more sensitive information, the investigator would likely be subject to personal feelings that may unduly influence their professional medical judgment. However, there may be exceptions. For instance, if the child is ill and a Phase II or III trial offers the greatest chance of potential benefit, or the child has a rare disease and each case can provide valuable data, the case should be presented to the IRB for consideration on a case-by-case basis.⁸

Summary

All parents want the best for their children- for them to be happy, healthy, successful, and safe. Parents determine if their child should participate in research, and parents have a moral obligation to protect their child from harm.⁹ Enrolling one’s child into personal research may result in harm and even worse care if the study does involve treatment. Percival’s *Medical Ethics*, published in 1803, argued for “the separation of professional and personal identities in the care of family members.”¹⁰ Akin to Percival, modern medical societies like the American Medical Association (AMA) state that physicians “generally should not treat themselves or members of their immediate families.”¹¹ Literature has shown that doctors can be guided more by personal feelings than medical opinion when treating family members. Moreover, they may simultaneously fail to probe sensitive topics, leading to a poorer standard of care.¹²

Enrolling a child into research evokes similar issues. When that patient or research subject is one’s own child, the medical professional is challenged to maintain their professional objectivity and risks coercion, whether intentional or not. Special consideration must always be allocated to these cases and carefully reviewed by a respective IRB or ethics team.

Researchers’ own child will always prove easily accessible and cases such as this are certain to arise again in the future. In this specific case, by ensuring that the data consists solely of objective measurements, professional objectivity can be maintained and harm is unlikely for the child given the nature of the measurements needed for participation. Given IRBs do not standardly monitor the identity

of participants, IRBs have been called upon to create clear policies about participation of children in their parent's research to avoid ethically suspect enrollment.¹³

¹ Lois L. Shepherd, Katherine Read, and Donna T. Chen, "Children Enrolled in Parents' Research: A Uniquely Vulnerable Group in Need of Oversight and Protection," *IRB: Ethics & Human Research* 35, no. 3 (2013): 1-8.

² Belluck, Pam. "Test Subjects Who Call the Scientist Mom or Dad." *The New York Times*, The New York Times, 18 Jan. 2009.

³ AMA Code of Medical Ethics Opinion 1.2.1 (2016)

⁴ Lois L. Shepherd, Katherine Read, and Donna T. Chen, "Children Enrolled in Parents' Research: A Uniquely Vulnerable Group in Need of Oversight and Protection," *IRB: Ethics & Human Research* 35, no. 3 (2013): 1-8.

⁵ *Ibid.*

⁶ Can I enroll my own child in research? Human Research Protection Program and Institutional Review Board, Oregon State University, 2019.

⁷ Resnik DB. Parent-investigators: a dilemma. *JAMA*. 2009;301(20):2159-2161. doi:10.1001/jama.2009.728

⁸ *Ibid.*

⁹ *Ibid.*

¹⁰ Chen FM, Feudtner C, Rhodes LA, Green LA. Role conflicts of physicians and their family members: rules but no rulebook. *West J Med*. 2001;175(4):236-240. doi:10.1136/ewjm.175.4.236

¹¹ *Virtual Mentor*. 2012;14(5):396-397. Doi: 10.1001/virtualmentor.2012.14.5.coet1-1205

¹² *Ibid.*

¹³ Resnik DB. Parent-investigators: a dilemma. *JAMA*. 2009;301(20):2159-2161. doi:10.1001/jama.2009.728